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Exemplar models and support for older carers and carers of people with dementia: informing commissioning: Executive Summary

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Executive Summary

NHS England Commitment to Carers

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Introduction

In May 2017 NHS England commissioned a project to support its Commitment to Carers programme. The focus of the work was to scope exemplar models of support for older carers, and for carers of people with dementia (of any age). The work took place between May 2017 and March 2018, and included a consultation workshop in February 2018. A full report of the findings is available, but this brief summary has been prepared primarily to give feedback to the people who contributed to the project and shared their experience with us.

Our conclusions and recommendations should inform the further development of NHS England's Commitment to Carers, but more widely they also point to gaps in which new approaches might be further developed and tested, building on the experiences and exemplars discussed.

The Policy Context

Support for carers needs to be considered within the context of the national policy agenda for health and care. The Department of Health sets an annual mandate for NHS England and in 2014 it stated that the NHS must *"become dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment"* (Department of Health, 2014). In responding to the mandate, NHS England developed its Commitment to Carers and identified 8 priorities (NHS England, 2014a):

- Raising the profile of carers.
- Education, training and information.
- Service development.
- Person-centred, well-coordinated care.
- Primary care.
- Commissioning support.
- Partnership links.
- NHS as an employer.

Further context for any developments supporting carers comes from the 2014 Care Act (HM Government, 2014). The Act created parity of esteem between carers and those they support, strengthened carers' rights to an assessment, and created a new duty on local authorities to meet carers' eligible needs.

The Act also created new duties for local authorities to promote wellbeing, including delaying and preventing care and support needs, and supporting people to live independently for as long as possible. There is also a duty to cooperate, and of integration. Local authorities must carry out their care and support functions with a view to ensuring integration with health and health-related provision.

The NHS Five Year Forward View, and the Next Steps iteration provide the strategic direction for the NHS, and also underlined the importance of a new relationship with patients and communities (NHS England, 2014b, 2017). In addressing prevention objectives, the Forward View identified the need to *"find new ways to support carers"*, particularly the most vulnerable groups of carers such as those aged over 85. The Next Steps document once again underlined the need for further action to identify and support carers, and particularly to reduce carer breakdown and improve carer health-related quality of life.

More specific policy objectives for supporting carers have been located in the National Carers Strategy, first introduced in 1999, and developed through various updates in the years since. A 'Carers Action Plan' was published in June 2018 and emphasised that the needs of carers will also be central to the forthcoming social care green paper (Department of Health and Social Care, 2018). . The action plan announced the creation of a Carers Innovation Fund to develop and promote creative and cost-effective models and carer-friendly communities.

Messages from Research

The project for NHS England builds on existing knowledge and research and was informed particularly by an earlier scoping review undertaken by the same research team (Henwood, Larkin, & Milne, 2017).

Older Carers

The focus on two groups of carers for the NHS England project (older carers, and carers of people with dementia), makes sense for a number of reasons. Older carers are likely to be sharing a household with the person they support and as a result are likely to be more heavily involved in caregiving (Milne & Hatzidimitriadou, 2003). Caring typically takes place within a long term relationship, and there is often considerable mutual support (or 'co-dependency'). As couples age, the carer is likely to have their own health and disability issues to cope with alongside caring demands, and among the very elderly there is a likelihood of the person they care for having dementia with associated behavioural and personality changes.

Not all older carers are caring for a spouse or partner, and some will have life-long caring responsibilities for a disabled adult son or daughter, particularly those with learning disabilities. This group of carers can be especially vulnerable, with the strains of long term care alongside their own deteriorating health and concerns about the future of their adult child (Perkins & Haley, 2013).

Carers of People with Dementia

Most – but not all – people affected by dementia are elderly, and the same is true of their carers. Dementia is a complex progressive condition which causes a loss of cognitive, functional and mental capacities (Bremer, Cabrera, Leino-Kilpi, Lethin et al., 2015). Because of the intensity and range of care needs over time, dementia is often linked in research with the topic of 'carer burden'. Thus, higher intensity of caregiving is typically associated with more negative health outcomes for carers. However, the strongest predictor of poor outcomes for carers is the presence of behavioural problems (agitation and aggression) in the person being cared for. This may be partly because such behaviour increases the social isolation of carers – there is evidence that carers of people with dementia report fewer opportunities to socialise and less social interaction and friendships than do non-carers (Charlesworth, Tzimoula, Higgs, & Poland, 2007).

Most of the research and knowledge about caring for people with dementia is based on the experiences of people from white backgrounds and it is recognised that there are challenges with cultural awareness of dementia among minority ethnic South Asian communities. This can lead to low rates of diagnosis and increased pressures on carers (Carers UK, 2011).

Dementia can also affect people at younger ages, and those who are aged under 65 are referred to as having 'young onset dementia'. The needs of carers, and those they support, who have a diagnosis of dementia while still relatively young are distinctive and have been the focus of relatively little awareness or research attention.

Around 5% of people with dementia have young onset, and although they will have many similar needs to older people with dementia, they also differ in important ways. The impact of the condition on carers and the wider family is also likely to be significant given the stage of the lifecycle at which diagnosis occurs. The Alzheimer's Society points out that younger people with dementia are more likely to: still be in paid employment; have a partner who works; have dependent children; have older parents to care for; have a mortgage and other financial commitments; be more fit and physically active; and have a rarer form of genetic dementia - which can have implications for their children (Alzheimer's Society, 2008).

Lack of public and professional awareness and understanding of younger onset dementia can increase the stigma for carers and those they support. The psychological impact of diagnosis on people and their families is also likely to be profound. Not only do people have to face the shock of diagnosis, but they do so with increasing worry about how they will cope both financially and practically (Rosness, Mjorud, & Engedal, 2011).

Models of Support

In looking at exemplar models of support for older carers, and carers of people with dementia, we drew on existing knowledge and research about 'what works'. Firm evidence for the effectiveness of specific interventions to support carers is thin. Two meta-reviews of international evidence have concluded that the best evidence is around interventions that enhance carers' knowledge and skills (such as education, training and information) (Parker, Arksey, & Harden, 2010).

Thomas et al similarly found that most models of support have not been evaluated, but evidence on what makes a difference to carers points to contact with others outside carers' normal networks (Thomas, Dalton, Harden, Eastwood, & Parker, 2016).

Parkinson et al have proposed that what unites disparate interventions that seem to be of value of carers appears to be how they contribute to strengthening carer resilience (Parkinson, Carr, Rushmer, & Abley, 2016). They suggest this includes five key areas: extending social assets; maintaining carer's physical health; carer's quality of life; availability of external resources, and strengthening psychological resources.

Models of Support & the Third Sector

Our understanding of the policy and research context informed our approach to exploring these issues further with key third sector organisations. Our approach was in two parts, beginning with an on-line survey. A total of 19 organisations were invited to participate, including the key national carer organisations, but also other organisations likely to be involved in supporting carers because of the nature of their condition-specific focus and interest.

Completed surveys were returned by 9 of the 19 organisations (and two of the 19 declined to participate). The responding organisations were:

- Age UK
- Carers Federation
- Carers First
- Carers Trust
- Carers UK
- Dementia UK
- Parkinson's UK
- Royal Mencap Society
- The Stroke Association

We are very grateful to these participating organisations for their assistance with our work. We offered anonymity to respondents, and we do not identify individual interviewees; however, some of the exemplars of models of support are particularly distinctive and may be more easily identified. Where it was not possible to disguise the service, we have obtained permission to identify it.

The survey explored organisations' involvement in supporting older carers and carers of people with dementia through a range of services including: the use of volunteer networks; coping/educational interventions; respite services; technological support and interventions; memory services; dementia cafés (and similar models); befriending and peer support etc. We were interested to capture innovation, and to examine evidence of evaluation where possible.

The survey was also an opportunity for us to invite expressions of interest from participants who wished to be involved in a second stage of the project enabling us to explore findings in greater depth.

The models of support provided for carers of older people identified most frequently by respondents were:

- Befriending and peer support,
- and educational/coping support – developing carer resilience.

Responding organisations were also likely to indicate that they provided support to older carers in rural communities; to BAME communities and to LGBT groups. However, comments made by respondents indicated that – in the main – this was indicative of an inclusive approach to provision, rather than a specific focus of services, as the following comments highlight.

"no specific activity currently, but all support open to all."

"We do not offer specific support to this group of carers but all of our services and support are open to everyone (…) including carers of people with dementia."

"We are developing a leaflet for all LGBT carers, which incorporates dementia."

When asked about models of support developed specifically for carers of people with dementia, other than older carers, few respondents identified examples, but again emphasised an inclusive approach in service provision.

Six of the responding organisations wished to be involved in further exploration of models of support, and additional contacts were identified through the research team's networks. Interviews subsequently took place with 13 participants.

Interviews generated a rich source of qualitative data; all interviews were digitally recorded and transcribed. Analysis of themes was undertaken using NVivo software.

Before turning to the analysis, some general reflections are worth making. It was apparent that organisations that work with carers have detailed understanding and insight from their direct knowledge of carers and their circumstances and lived experience. Many of the comments made during interviews reinforced messages and knowledge from the wider research literature. This was evident both in respect of older carers and for people caring for those with younger onset dementia. In the case of the former, the interviews drew attention to the particular pressures for older carers, especially when they are coping with their own poor health and frailty. In the latter, the difficulties for people with younger onset dementia and for their families emerged as multiple and complex, not least in getting a diagnosis but also in managing the far-reaching consequences and impact.
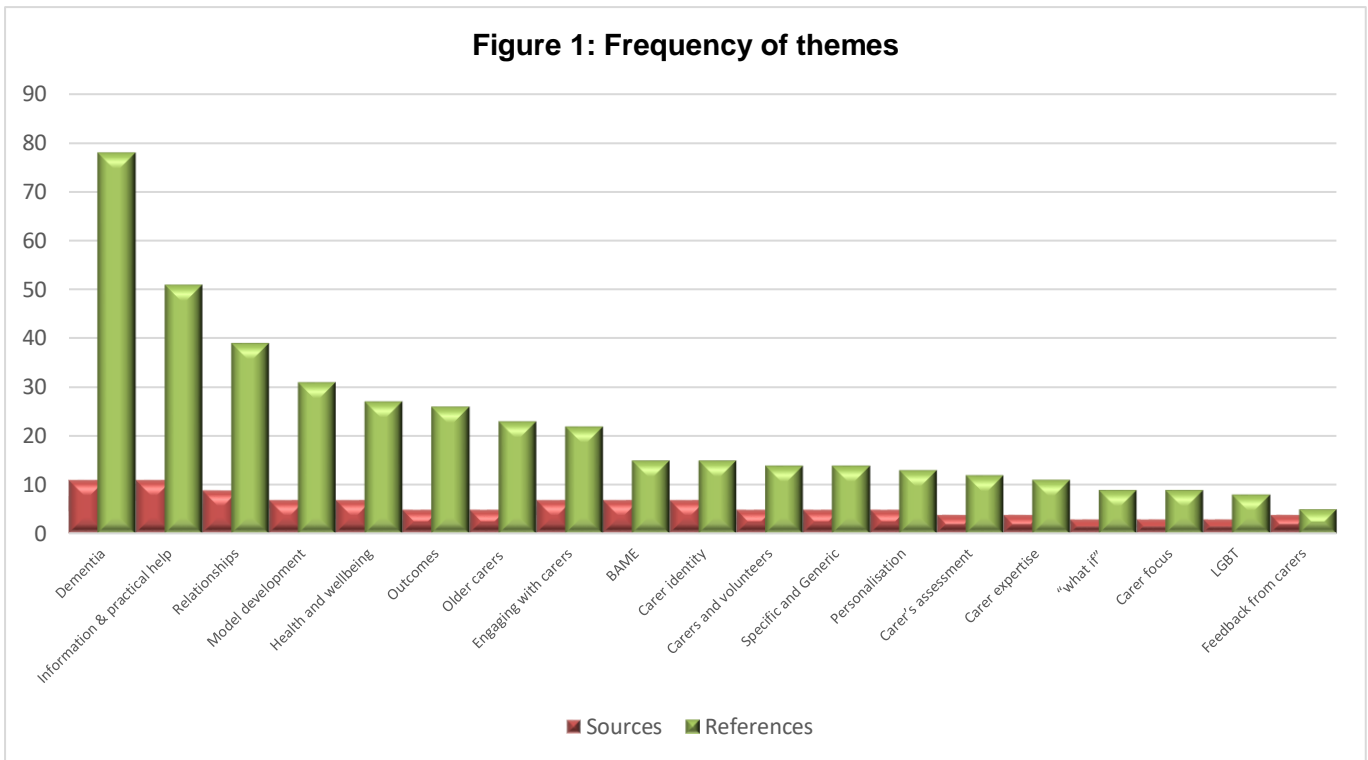
Themes & Issues

Figure 1 below presents a visual summary of the major themes and issues identified through analysis of interviews. This does not necessarily represent models of support or interventions, but also the major themes in the understanding and perspectives of interviewees in regard to older carers, and carers of people with dementia.

Interviewees commented on the particular needs and situation of older carers, often pointing out their isolation, and also the hidden nature of this group of carers, as these comments illustrate:

"The big thing, particularly with older carers, is around reducing isolation and loneliness."

Figure 1: Frequency of themes

Figure 1: Frequency of themes (bar chart showing Sources and References across themes: Dementia, Information & practical help, Relationships, Model development, Health and wellbeing, Outcomes, Older carers, Engaging with carers, BAME, Carer identity, Carers and volunteers, Specific and Generic, Personalisation, Carer's assessment, Carer expertise, "what if", Carer focus, LGBT, Feedback from carers)

"(…) carers over the age of 80, you don't come across them until they're in an acute situation. So that's if somebody's been admitted to hospital or there's been a complete breakdown of the situation and we're not identifying people early."

As the wider literature and knowledge about caring has documented, many carers do not identify themselves as such, and this is particularly likely to be the case with older carers who have been in a relationship for many years, as this comment highlights:

"a lot of times with people 'carer' is a new kind of word, and if you look at it on average it takes people two years to identify as a carer. And we kind of need to change the word, a bit more about 'do you look after somebody?' or 'do you help somebody?', you know, because the word 'carer' – people say 'I'm not their carer, I'm their wife!' it's what I do, I do it; they're my family."

The theme of dementia, including carers of people with dementia, was the focus of more comments and observations by interviewees than any other topic. Although there can be considerable overlap between older carers, and carers of people with dementia, the needs of carers are both similar and distinctive.

Awareness and understanding of issues impacting on carers of people with early onset dementia revealed a different set of concerns from those affecting older carers. In particular, interviewees pointed to the substantial impact that could affect entire families because of their stage of life, and introduce extreme stress in relationships, as this comment underlines:

"They're still in work; they've got a mortgage; they've got youngish children or children at university. They had a future ahead of them, a retirement future, that will never be realised (…) and I think that loss and that grief reaction from not only the person with dementia but their carer, can be huge."

Models of Support

A wide range of activity and support for carers was identified in the course of the fieldwork. Some of this was generic – supporting carers of all types – and some was more specific, being designed for and targeted at particular groups of carers. The major cross-cutting themes clustered around the following:

- Information & practical help (including sub-themes of: beyond diagnosis; signposting; locally based community support; respite; carer hubs, and dementia hubs).

- Relationships (including sub-themes of: peer support; co-dependency; and organisational relationships).

- Model development (including contracts and tendering).

- Outcomes.

It is not always a specific intervention alone that makes a difference to carers, but it is the style of the service, and a combination of elements that provide valued support for carers and contribute to their resilience and capacity to sustain their identity. In particular, it is not simply the 'what' of a service, but also the 'how'; or what is distinctive about the approach of a service or a specific intervention that is valued by those who use it.

Getting appropriate information at the right time is a frequent theme in carer research and knowledge, and this was underlined in the present study. For some carers there is a more direct pathway into information, particularly when there is a sudden onset of caring responsibilities such as following a stroke. For others – notably where the carer role develops over a period of time – access to information may be less obvious. Voluntary organisations recognise the particular challenges of getting information to people, especially to older and other 'hidden' carers.

Voluntary organisations have a vital role not only in providing information directly, but also in appropriate signposting to other sources of help, as this comment highlights:

"Understanding and developing our knowledge of what other organisations do, especially for the carers, and where we can make use of their resources and signpost people to them, rather than trying to recreate everything."

Having **a 'life beyond diagnosis'** was identified by several interviewees, and was particularly important for people with younger onset dementia where they might have many years of living with the condition. Interviewees were aware of people not getting appropriate support following a diagnosis, and indicating an attitude that nothing can be done:

"It's almost like, you get the diagnosis and that's the end."

"You know lots of GPs say 'well we only refer if we think there's going to be a point to referring'."

And

"[people] tended to get the diagnosis, and then tended to be released back to the GP, which is fine, but the GPs generally don't have the time or the expertise to work with people living with dementia."

Interviewees identified a **range of locally-based community support services** developed to meet the needs of carers (and the people they support). Some were particularly focused on early intervention and prevention, and in response to asking carers what would be most helpful to them, for example:

"Support that enables them to go along with the person they care for, because quite often in the past there have been separate carers groups, which actually creates a barrier in terms of accessing support because there might be issues

around the cost of care, around transport, so we look at all of that."

Organisations described 'carer hubs' that were open to both carers and those they support, but with opportunities for the groups to split and have their own time. Having 'me time' and social contact were frequently identified as important, as was the wider role of peer support between carers. The role of different types of respite was identified, and some of the most innovative approaches were around models of support for younger people with dementia (www.ypwd.info). Here the emphasis was on offering age appropriate, meaningful occupation for people aged under 65 with a dementia diagnosis, while simultaneously providing structured respite support to the carers of those people through a workshop. Both separate and shared activities for carers and people with dementia featured within this approach.

The importance of developing suitable activities and engagement for younger people with dementia was a powerful motivator in developing this model:

"Most 50-year olds really would not access day care where the average age of people was over 80. Nor would their carers – their spouses, partners, would say well no, that's not appropriate!"

Similarly, focusing on what people *can* do, rather than what they *can't do* can produce a more dynamic model of support than conventional day services that some interviewees described as little more than a 'holding centre'. By contrast:

"That's quite useful for the families because it's somewhere that's safe and they can go out and do what they need to do (…) But for the people that are living with the diagnosis – unless they are doing something that they are interested in, they are not a lot of use."

The importance of **supporting relationships** within caring was widely

recognised, as was the variety of situations and circumstances this includes, for example:

"Everybody's caring situation is different; every family is different. Some people may be in a very difficult situation where they might not have had a positive relationship, then they find themselves caring (…) 24 hours a day, seven days a week."

Similarly, caring changes the nature of relationships and role expectations. Not all caring relationships are entered into willingly, but also from a sense of obligation and lack of choice. The additional strains of this both on the carer and on the person they care for who may realise the person doesn't really want to be a carer, are apparent. Support for carers in such circumstances may need to include counselling, problem solving skills and enabling carers to develop their own coping mechanisms and resilience. Understanding the nature of dementia and training carers in the implications of the condition can be a critical part of supporting them to cope, particularly in understanding the behavioural and psychological changes in a person.

The **development of models of support and monitoring of outcomes,** and seeking contracts for commissioned services, were recurrent issues explored with interviewees. The impact of austerity on public services, and on the availability of support for third sector initiatives was widely cited, and some of the interviewees either did not know if they would have a job in the next financial year, or had already been told that their contract was finishing because of lack of funding. People described a sense of operating 'hand to mouth', and the problems of uncertainty in the absence of robust and reliable funding streams, as these comments illustrate:

"There's a lot of uncertainty – we train and we develop staff, and we have such brilliant passionate staff and then they

have to move on because we don't know from one year to the next what's happening."

And

"This is a problem for lots of organisations – the NHS commissions on a yearly basis. So, it is very hard if you're a small organisation. You want staff to be on permanent contracts, but it isn't safe that you'll get the funding next year. So we had a few years of that. And then when the Better Care Fund came out we took our data to the Clinical Commissioning Group and now we get some of our funding from them."

Monitoring and reporting on commissioned services are often poorly developed and are not focused on appropriate metrics or outcomes. Typically, monitoring is concerned with activity counting, or fails to take account of qualitative dimensions of outcomes.

It was relatively rare for organisations to develop models of support within a framework that articulated a 'theory of change'. This is an important finding with implications for future initiatives; without clarity over the nature of a given intervention, and the intended objectives, it is not possible to draw firm conclusions about achievements or outcomes – or indeed to have clarity over the appropriate parameters of those outcomes and how to measure them. Such conclusions are relevant - and indeed vital - both to providers seeking to develop and extend the reach of their services, and also to commissioners wanting to support such developments and needing to establish more sophisticated and accurate ways of evidencing effectiveness that progress beyond enumerating activity.

Conclusions and Recommendations

Our project findings – based on sequential stages of an on-line survey and more detailed qualitative interviews – have been summarised above. We took the emerging findings and conclusions from this work to a consultation workshop with key stakeholders in February 2018, and there was widespread support and endorsement of the conclusions. Reflections and discussions at the consultation further informed our analysis. A graphic summary of the issues discussed in the workshop reproduced below (with thanks to Pen Mendonça).

Our conclusions have echoed and reinforced many of the central messages identified in the wider research and knowledge about supporting carers. Thus, for example, we found befriending and peer support, and approaches focusing on developing carer resilience were highly valued. Furthermore, we have underlined that the style of support, and the manner in which it is provided can be crucial. Thus, support is not always about a single intervention, but about a combination of factors, reflecting both the 'what' and the 'how' of support.

Evaluating the effectiveness of interventions, and assessing the outcomes achieved, is often relatively unsophisticated and undeveloped. There is a need for greater clarity about the purpose and objectives of interventions, and how these are to be achieved. In turn this creates greater clarity about appropriate reporting and performance measures. This is of particular importance in respect of commissioned services, and requires CCGs and local authority partners, for example, to have a better understanding of the objectives of interventions developed by third sector bodies, and the relevance of outcome measures to assess achievement. It is important that these address

both quantitative and qualitative dimensions, and move beyond basic counting of activity, while not making unrealistic expectations about achievements (such as demonstrating reduced residential and hospital admissions) over a short time scale, and without taking account of wider variables that may impact on delivery.

In order for third sector bodies to develop models of support, to have opportunities to examine effectiveness and to scale up successful initiatives, some level of security is required with commissioning. Short term contracts or annual tenders are not conducive to such developments, particularly for smaller organisations that do not have the capacity to invest in project development and staff employment without a reliable funding stream.

We have identified some innovative developments for older carers and carers of people with dementia, and also highlighted some areas where further attention is needed (such as with the specific needs of BAME and LGBT carers within these groups). There would be merit in exploring more fully some of the models and in supporting their adoption in other sites. This includes the following:

- **Building carer resilience** through techniques for coping and understanding: providing the right information and training for carers in understanding the condition of the person they support, and in developing techniques to manage the demands.

- **Reducing isolation and loneliness**: this is a major factor in addressing the mental health and wellbeing for carers and in preventative intervention. Social contact and peer support are particularly valuable components.

- **Living a life beyond diagnosis**: this is especially relevant for people caring for someone diagnosed with dementia. Recognising that the condition is progressive,, but taking the

opportunities to enhance daily life. Crucial to this are appropriate and timely diagnosis and referral, which have major implications for GPs and other health and care staff.

- **Reimagining respite**: recognising that respite is also about breaks from the usual routine for both carer and cared for person. Some features of innovative approaches for people with younger onset dementia that emphasise meaningful activity and engagement need to be more widely adopted. What might this look like for older people and their carers?

- **Space and scope to expand**: commissioning models of support within longer timeframes that allow scope for development and achievement and do not cause additional pressures of year on year uncertainty of funding.

Further Information

Further information can be obtained by contacting the research team through Dr Mary Larkin at the Open University.

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Workshop Graphic Summary

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NHS England: Commitment to Carers

THE DANGOOR UMBRELLA

You say that the ones we love are putting pressure on the health & social care system

Yet the vast majority of care needs are met by us: family members, lovers, friends = carers

Like an upturned umbrella, stable or perhaps frail, or struggling in the wind & rain

THE RIBS ARE LIKE INTERVENTIONS FROM PUBLIC SERVICES, VOLUNTARY SECTOR, SOME WEAKENED SOME MISSING

The carer keeps everything going, regardless of what you do we continue to care & to love

VALUE OUR LOVED ONES, VALUE CARERS

Based on a concept by Margaret Dangoor, Graphic Facilitation by @MendoncaPen www.penmendonca.com 2018, thanks to Melanie Henwood OBE

Footnote: The analogy of the 'upside down umbrella' was outlined at the consultation workshop by Margaret Dangoor, a former carer. She explained that the idea of an umbrella adrift on the water represented the precariousness of many caring situations. Carers provide the fabric of the umbrella and hold everything together, while interventions from statutory and voluntary sector services are represented by the ribs, but these are often missing or broken. In liaison with Margaret Dangoor and Melanie Henwood, Pen Mendonça subsequently designed the graphic reproduced above.

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